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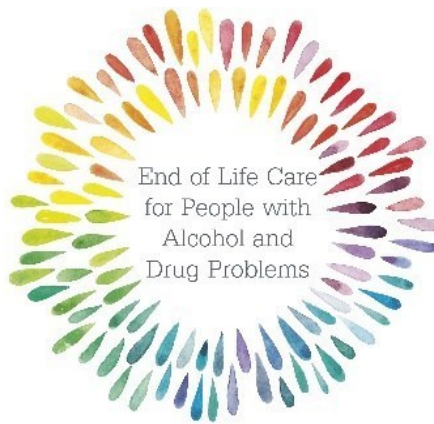
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# **End of Life Care for people with alcohol and other drug problems**

## **Report on Phase 1 of Strand 4: Family member, friend and carer experiences**

**Secondary analysis of interviews with family  
members, friends and carers bereaved through a  
relative's substance use**

**Dr Sam Wright, Dr Gemma A Yarwood, Lorna Templeton and  
Professor Sarah Galvani**

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## **Acknowledgements**

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## Executive Summary

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1. This research presents findings from secondary analysis of qualitative interviews with adults bereaved through substance use. As the first half of a two-phase piece of work, this analysis aimed to:
  - explore how families of people with alcohol/drug use problems experience their relative's end of life;
  - examine the extent to which services recognised or responded to the whole family's needs; and
  - inform design and delivery of primary qualitative data collection (the second half of the two-phase piece of work).
2. The research team accessed interview transcripts from an ESRC funded research project on Bereavement Through Substance Use, where 102 people talked about the deaths of 93 relatives/friends.
3. The secondary qualitative analysis used NVIVO 10 to facilitate a combined thematic and template analysis approach to organising and analysing the data.
4. Three main themes emerged from the data: (1) health and social care practitioner identification and communication about approaching end of life to the person and/or their family; (2) missed opportunities for providing substance use treatment and/or healthcare to the individual with alcohol/drug problems; and (3) family support needs (formal and informal).
5. Our findings for the first theme highlighted key differences among the sample with regards to the extent to which death was anticipated and the level of communication and support from health and social care practitioners. Our findings reveal that only 18 out of 93 described deaths entailed health and social care practitioners identifying and communicating the relative's approaching end of life care to their families.
6. The second analytical theme highlighted twenty-one examples of 'missed opportunities' whereby health and social care practitioners did not intervene in recognisably harmful levels of substance use by individuals among the group where there were associated indicators of deteriorating health. Furthermore, there were no mentions of the involvement of, for example, palliative care teams or hospices.
7. The third main theme - family support needs – revealed that the families often had health and social care needs of their own. Sadly, despite clear evidence of the prolonged strain that they were under, their attempts to seek help over the years had rarely proved successful and their lack of support often continued after their loved one's death.
8. For families where there are alcohol/other drug problems, practitioners need to be able to openly discuss substance use, explicitly recognise the long-term stress they may have been experiencing, and counteract the shame or stigma that family members may be feeling. This is necessary not only to provide more person-centred care, but also to improve working relationships between practitioners, families and people approaching the end of their life.
9. Health and social care practitioners' recognition of the strain and frustration that the whole family may have experienced is important to improve communication and allow for a crucial degree of openness and tenderness between families and their relatives during the final period of their life.

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## 1. Introduction

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The programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* (funded by the Big Lottery Fund) has six strands. This report presents data from one strand (strand 4) of this project. The aim of this particular strand was to focus on how families, friends and carers (hereafter ‘families’) of people with problematic alcohol and drug use (hereafter ‘substance use’) experience their relative’s end of life care.

Strand 4 has two phases. This report focuses on phase one: secondary analysis of interviews with adults who were bereaved as a result of their relative’s substance use<sup>1</sup>. Phase one informs the design and delivery of the primary qualitative data collection with families, phase two.

This secondary analysis drew on interviews with 102 people who spoke about the deaths of 93 relatives and friends (hereafter ‘relatives’). By undertaking a combined thematic and template analysis of these interviews (Braun and Clarke, 2006; King et al., 2004; Willig, 2012), we explored how the families experienced their end of life care. To begin with, we considered whether and how health and social care staff (hereafter ‘care professionals’) identified and communicated with families about their relative’s end of life care. We explored the extent to which either substance use and/or end of life care services recognised or responded to the relative’s and/or the family’s needs.

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## 2. Research design, methods and sample description

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This section describes the research design including the data sample and data analysis process. The aims of this secondary analysis were to:

1. explore how families of people with problematic alcohol/drug use experience their relative’s end of life;
2. examine the extent to which services recognised or responded to the whole family’s needs; and
3. inform design and delivery of phase 2, the primary qualitative data collection.

The interviews analysed for this report were conducted between February and December 2013 in England and Scotland as part of a research project on Bereavement Through Substance Use (Templeton et al., 2016; Valentine et al., 2017). Accessed through a range of sources, interviewees described a wide variety of bereavements, with their relationships to the deceased person including those of parents, children, spouses, siblings, nieces and friends. All interviews were audio recorded, fully transcribed and stored in the ESRC data archive<sup>2</sup>.

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<sup>1</sup> The interview data analysed for this report were originally collected for a separate research project on Bereavement Through Substance Use conducted in 2013.

<sup>2</sup> The original bereavement study conducted 100 interviews with 106 adults but four interviewees did not consent for their data to be placed in the ESRC archive, hence the slightly smaller sample available to us for this secondary analysis.

Table 1 (below) outlines the demographics of the relatives who had died and about whom the family members were speaking:

*Table 1: Key demographic characteristics of the deceased relative*

Demographic characteristic	Percentage
<b>Relative's gender</b>	Male: 80% (n=74 of 93) Female: 20% (n=19 of 93)
<b>Relative's relationship to the interviewee</b>	Adult child: 47% (n=44) Parent: 19% (n=18) Partner: 14% (n=13) Sibling: 12% (n=11) Friend: 5% (n=5) Aunt/Uncle: 2% (n=2)
<b>Relative's substance use</b>	Drug use only: 47% (n=44) Alcohol only: 30% (n=28) Alcohol and drugs: 23% (n=21)
<b>Relative's age</b>	Mean age: 37 years (Range 16 - 84 years)
<b>Place of death</b>	Home: 37% (n=34) Hospital: 26% (n=24) Other domestic: 16% (n=15) Outside (Public spaces): 10% (n=9) Other: 6% (n=6) Unknown: 5% (n=5)

As Table 1 shows, 80% of the relatives were male, which is representative of the substance using population. In this sample, a higher percentage of relatives used drugs only than alcohol only with just under a quarter using both substances. The relative's relationship with the research participants was predominantly a familial relationship (including adult child, parent, sibling and aunt/uncle) or partner. Only five per cent were identified as friends. For this reason we have chosen to adopt the term families - while recognising that five per cent were friends and not family members. In terms of the age, the deceased relative ranged from 16 to 84 years old, with the mean age being 37 years. Table 1 also shows that the place of death varied, but that the relative's home and hospital were the two most common locations.

## **2.1 Key demographic profile of the interviewees**

In addition to Table 1 above, we also summarised the key demographic profile of the interviewees.

Just under two thirds (62%; n=63) lived in England, whilst 38% (n=35) lived in Scotland. In contrast to the relative's identifying largely as male (80%), the majority of interviewees were female (74%; n=75) with a mean age of 52 years (range: 22 – 75 years old). In comparison, the mean age of relatives was only 37 years old.

Just under a half of the interviewees (48%; n=49) were parents talking about their adult children who had died, whilst a fifth (20%; n=20) of interviewees described the death of one of their parents. The remaining interviewees were partners or ex-partners of the deceased (13%; n=13); siblings (12%; n=12); friends (5%; n=5) or nieces/nephews (2%; n=2). Twelve of the interviewees (13%) were/had been in alcohol or drug treatment themselves. The length of time since their bereavement varied enormously: from 6 weeks to over 30 years prior to the interview. Only two interviewees described bereavements that had occurred over ten years previously and with our focus being on identifying support needs (rather than evaluating any services provided), their valuable experiences were included in the study despite having taken place many years previously.

## **2.2 Qualitative Interview Data**

This section sets out the steps undertaken to collect and thematically analyse the interview transcripts using a combination of template analysis and thematic analysis (Braun and Clarke, 2006; King et al., 2004; Willig, 2012). We explored how families experienced the relative's end of life, and the extent to which care professionals recognised or responded to the whole family's needs.

The ESRC data archive contained transcribed interviews that provided rich qualitative data about the end of life for their relatives who had had substance use problems. The interviews had originally been conducted between February and December 2013 in England and Scotland with participants accessed through a range of sources (Templeton et al., 2016; Valentine et al., 2017). All interviews were audio recorded, fully transcribed and 102 of the original 106 participants consented to the transcripts of their interviews being stored in the ESRC archive.

### ***Using Secondary Analysis of Qualitative Data (SAQD)***

In recognition of the highly sensitive nature of the topics being investigated, Secondary Analysis of Qualitative Data (SAQD) was adopted to: (1) develop knowledge in this under-researched field, and (2) inform planned primary qualitative data collection. This SAQD process is described in more detail in Yarwood et al., (2018) which identifies some key strengths from secondary analysis, including:

- Overcoming participant recruitment challenges that arise because target groups are difficult to either reach (due to low incidence of the issue being studied, or 'hidden populations' of people not accessing services), and/or recruit - due to the topic being associated with feelings of distress, stigma and shame;
- Being an unobtrusive research method (Smith, 2008) that removes the burden of interview participation from both gatekeepers and potential participants who may be research fatigued or in emotional distress (Heaton, 2004);
- Being a cost-effective method in terms of minimising the time required for data collection and avoiding fieldwork costs;
- Providing knowledge to inform subsequent primary research, particularly in heightening awareness of sensitive and ethical issues.



Established thematic analysis techniques were used to identify and develop topics for enquiry (Braun and Clarke, 2006; King et al., 2004; Willig, 2012). Three members of the strand research team undertook preliminary reading of a sample of 10 of the transcripts. We compared, contrasted and discussed an initial template or coding frame of themes. Once we had agreed this initial coding frame, we individually re-read the original ten transcripts to pilot it. We then discussed, expanded and refined the coding frame. Once a final refined version of the coding frame had been agreed, the research team coded all transcripts.

It is important to note that the coding frame was developed through a process of revision, expansion and refinement by the research team using a computer-based software package (NVIVO 10). The main advantage of using this software was that it facilitated an auditable process of thematic analysis by organising and categorising the large number of transcripts by three researchers.

Below are the main themes that stemmed from this analytical process. These are accompanied by (for the purposes of brevity) examples of what was included in each theme.

- *End of life care*: This included identifying end of life care; communication between the relative, care professionals and families; the relative's end of life health and social care needs; and the families' experiences of their relative's end of life.
- *Missed opportunities for end of life and/or substance use care*: These included families' experiences of the relative's substance use; the relative's support needs (substance use and end of life); and whether or not these needs were recognised, and responded to, by substance use/end of life care services.
- *Family support needs*: This included the (un)recognised needs of the relative's family; how care professionals, services and sources of informal support responded (or not) to the families' needs.

Each of these three main themes are discussed in detail in the subsequent key findings section of the report.

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### 3. Key Findings

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The following section summarises the key findings from the secondary analysis focusing on the three main themes, namely: end of life care; missed opportunities for end of life and/or substance use care; and family support needs.

First, we consider differences in family experiences of care professionals identifying and communicating the relatives' end of life care. Second, we discuss missed opportunities by health and social care teams - in either hospital or community settings (herein care professionals) - to provide relatives with end of life care. Third, we explore family support needs and either community or hospital based health and social care services (herein care services). The final section asks: 'How can we better understand family experiences of end of life care for relatives with alcohol and drug use problems?' The conclusion notes the challenges to answering this question and the importance of this secondary analysis in informing the design and delivery of primary qualitative data collection with families.

#### 3.1 Family experiences of end of life care

In order to analyse family experiences of care professionals end of life care, we categorised the 93 relative deaths (described in the 102 family interviews) into six categories. These categories incorporated differences in care professionals' identification and communication of the relative's end of life and end of life care, to the families. The focus here is on what families described in the interviews. Given the need for confidentiality between the relative and care professionals, it is difficult to ascertain accurately the extent of communication between the relative and care professional about the relative's end of life care as the family member may not have the full picture. It is a relative's right to choose if, when and to whom, they talk about dying and their end of life care. Care professionals should respect this but it means that the families interviewed could have been unaware of communication between the professionals and the relatives about their end of life care.

The following categories represent a clustering of families' experiences of the relatives' end of life care:

- Six families described healthcare professionals (hospital nurses and hospital consultants) explicitly identifying and communicating to the relative and families about the relative's end of life care (n=6).
- Twelve families described the relative's end of life care being explicitly identified and communicated to families by care professionals (hospital nurses and hospital consultants) once the individual relative was unconscious (or slipping in and out of consciousness). Families described this late communication with them as leaving them with limited opportunity to discuss the relative's end of life care wishes because of the relative's limited capacity (n=12).
- Six families described the relative's end of life care not being communicated to them by healthcare professionals who were caring for the relative in a hospital setting. No other health or social care professional was identified as communicating with the family about the relative's end of life care. In these cases, it is difficult to ascertain

whether or not end of life was identified by the care professionals. If so, it is unclear whether care professionals had communicated this to the relative who may or may not have consented to sharing this information with their family. Families described having feared for the relative's potential end of life, but nevertheless conveyed shock at their death. Some families described this shock as being exacerbated by relatives having previously 'bounced back' from hospital treatment (n=6).

- Ten families described the relative's end of life in the relative's home as having little/no involvement from health or social care services. In this scenario, it is difficult to ascertain whether any care professionals had identified and communicated end of life to the relative. Families describe anticipating the relative's increased risk of the end of their life, but conveyed shock at the relative's death when it occurred (n=10).
- Sixteen families described the relative's death as premature, but referred to their awareness of the relative's increased risk of dying arising from recent health and social care crises (such as suicide attempts and/or overdoses). Families described end of life as potentially foreseeable in these cases, but generally had little contact with services and did not describe expectations that care professionals would be involved in supporting them or the relative at that time (n=16).
- Forty-three families described the relative's death as sudden, unpredictable and accidental (including murder and suicide). In these cases, there was no opportunity for care professionals to identify or communicate with families about the relative's imminent end of life or need for end of life care, and the families did not describe any such expectations (n=43).

In Figure 1 below, these differences in family experiences of care professionals identifying and communicating the relative's end of life care to them have been conceptualised.

The concentric model provides a clear summary of the differences and, to accompany this concentric model, we compared the data on: the relative's place of death; health condition warranting treatment/intervention; duration of final medical intervention and the relationship between death and alcohol/drug use. This helped us develop a fuller picture of the six categories of families' experiences of the services user's end of life. We have summarised the main features of the six categories in the concentric model below and then discuss each one in turn:

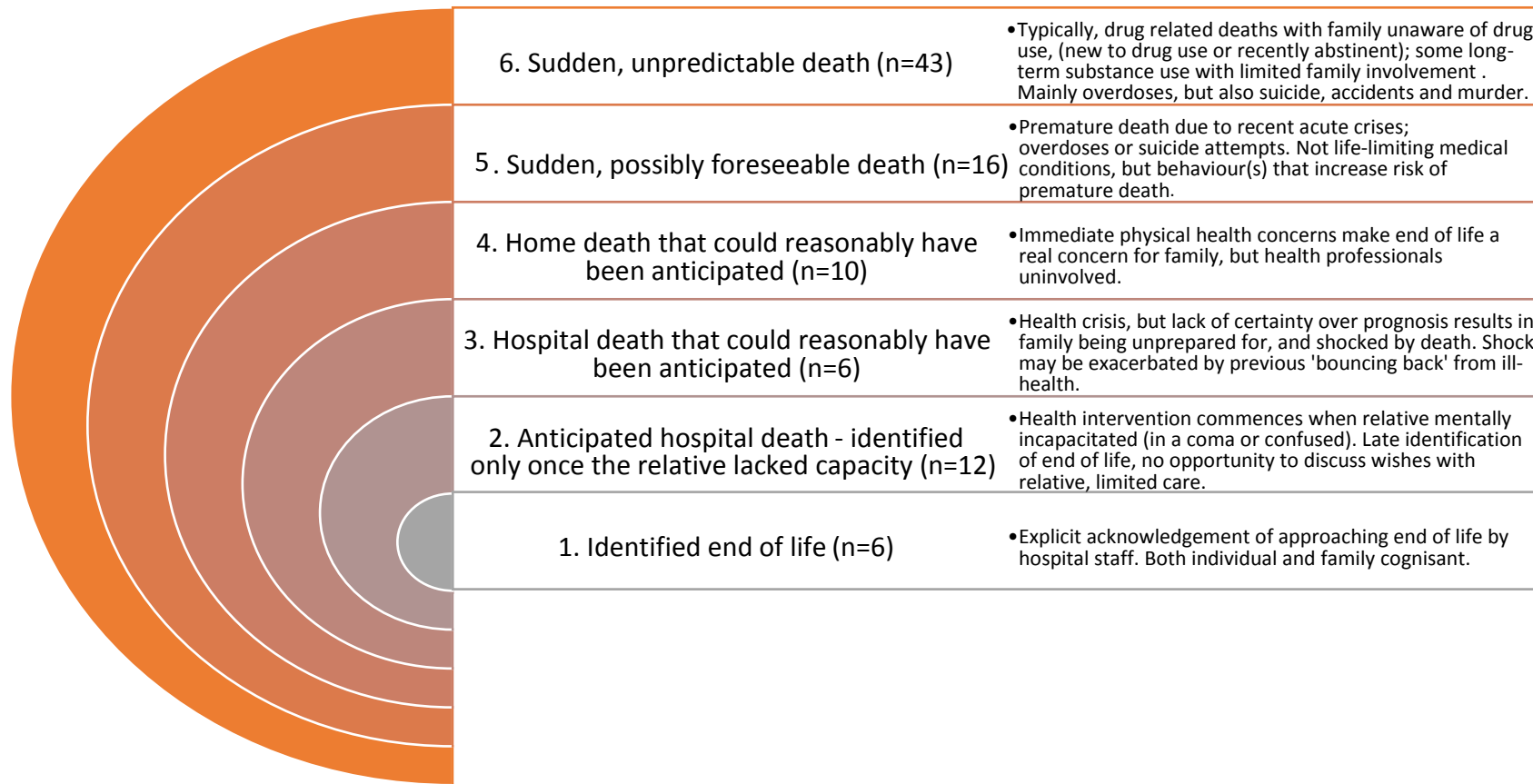


Figure 1: Conceptual circle of different degrees of anticipated death described for people with substance use problems

1. Approaching end of life explicitly identified and communicated to the relative and families (n=6).

- All of the deceased drank alcohol heavily, with half of them also having used drugs.
- The age range is quite young (mean age 42 years).
- There was a high proportion of males (83%).
- Four of the six life-limiting conditions were directly related to substance use (two alcohol and two drugs).
- On the whole, only very brief hospital interventions were experienced (the two-month treatment relates to cancer and the care was delivered at home).

2. The relative's end of life care was explicitly identified and communicated to families by care professionals once the relative was unconscious (n=12).

- Alcohol use features prominently among this group, whose age at death is young (mean age 48 years).
- Alcohol-related diseases (liver disease, kidney failure and encephalitis) feature prominently as causes of death.
- Average length of time in hospital is slightly longer than for the previous group.

3. The relative's end of life care is not communicated to families by healthcare professionals treating the relative in a hospital setting (n=6).

- Again, 100% of this group used alcohol heavily, with one person also having used drugs.
- This group has the highest proportion of women, and has a slightly older age profile.
- A combination of alcohol-related illnesses and co-morbidities are described (including diabetes and mental health difficulties).
- Length of time in hospital very short, families generally unprepared for relative's death.

4. The relative's end of life took place in their home with little/no involvement from health or social care services (n=10).

- Drugs feature in 50% of the cases, with no involvement of alcohol in 30% of the cases.
- The age profile is lower again (mean age is 35 years).
- Mainly alcohol-related causes of death.
- All home deaths, with some families concerned about imminent death for their relative.

5. The relative's premature death, following family recognition of increased risk of death due to recent health crises (such as suicide attempts and/or overdoses) (n=16).

- This group has a higher proportion of Scottish deaths than the previous groups.
- Drug-related deaths feature much more prominently in this group.
- The age range is again young, with a high proportion of males (mean age is 35 years.)
- Place of death more variable, with a range of causes that include a high proportion of overdoses and suicides.

#### 6. Sudden, unpredictable deaths (n=43).

- This group contains the highest proportion of Scottish interviews (47%).
- It has a much younger age profile than the other groups (mean age is 30 years.)
- Broad range of places of death.
- High proportions of overdoses, suicides and accidental death.
- The deceased was typically a young, male drug user – often the son of the interviewee - and many were either relatively new drug users or had been abstaining from drug use in the months prior to their death.

It is noteworthy that all of the Category 1-3 deaths, except one, occurred in hospital, and that in the cases where GPs were involved, this was mainly to refer patients to hospital. Alcohol-related deaths feature more prominently in the first three categories than for the overall sample. Much younger drug deaths feature in the final two categories (5 and 6), which reflect official statistics on Drug Related Deaths (Health and Social Care Information Centre, 2016).

Tables 2 and 3 in the appendix provide further details of the comparative data across the six categories of the concentric model.

The following section develops our knowledge and understanding of families' descriptions of seeking help or advice (either for the relative, or for themselves) with either substance use and/or end of life care services. We explored how families described the relative's end of life care and/or substance use care needs and the extent to which the family felt these needs were recognised or responded to by substance use and/or end of life care services. The following section describes missed opportunities by care professionals to: (1) recognise that someone was (possibly) facing a premature death, and (2) to initiate conversations and offer support to both the relative and their families.

### **3.2 Missed end of life and/or substance use care opportunities**

As discussed above, we found 21 clear examples of what we have defined as 'missed opportunities'. This means families described, to varying extents, their recognition that the relative was potentially approaching the end of their life but felt that care professionals missed opportunities to intervene in the relatives' recognisably harmful levels of substance use.

In many interview accounts, the relative with alcohol/drug problems had sought help from their GP or from alcohol/drug treatment services, but families described any reduction in the relative's substance use as short-lived. For example, a daughter of man aged 54 (who we have categorised in circle 1 of our concentric model), described her father as a serious alcohol user for many years. She was his main carer and noted that approximately two years before his death, he moved to nursing home. The nursing home staff knew about his alcohol use and told his daughter they would water down his whisky. Although he died in hospital, there was no mention of communication or support about palliative or end of life care from the nursing home or hospital until the man's last day.

Although several families stated that the relative had received warnings from their GP that their substance use (most commonly alcohol) could result in a premature death, many families described feeling frustrated and exasperated with the relative's continued drug and alcohol use. For instance, a niece who was interviewed about her 45 year old uncle (categorised in circle 3 of our concentric model), stated that three years prior to his eventual death he had been told he would die unless he stopped drinking. Yet, she conveyed shock and disappointment that there had been no conversations (that she knew of) with either the family or the relative, about his condition and his potential palliative or end of life care. She describes him being admitted to hospital with liver failure where he died a week later. She felt her uncle's end of life was rapid and she said she was unaware it was terminal.

Included in these examples of missed opportunities, families described repeated attempts by the family and/or relative to get help for acute health crises - such as GP consultations or repeated visits to A&E. Whilst focusing on the immediate health crisis, the family were often also hoping that something could be done to change the relative's longstanding substance use behaviour. For example, a step-sister interviewed about her relative, a 61 year old woman, (categorised in circle 3 of our concentric model) stated:

*When we were in and out of A and E, maybe we could have done with some help or advice or somebody [speaking] to us and saying: 'Look, you know, it's obvious your sister's got this problem, have you tried this? You know or have you tried contacting this organisation, or this?' Whatever, if there's help available, kind of make it aware.*

Step-sister aged 58 at time of bereavement.

Step-sister died aged 61.

The interviewee described her step-sister's history of hospital admissions associated with her alcohol use. Her step-sister had also been declined a liver transplant four months before death because she was too unwell. According to the family, despite the severity of the step-sister's substance use problem, there were no discussions about the potential need for the family to consider palliative and/or end of life care, despite repeated interactions with hospital staff (including liver transplant teams). The interviewee said that the family thought the step-sister would recover.

Whilst remembering that the original study focused on bereavement through substance use, this secondary analysis has developed knowledge and understanding on how families of individual relatives with alcohol and drug use problems experience the relative's end of life care. In most cases, families described limited, if any, explicit discussion between families and care professionals about the relative's risk of death. They noted that these were missed opportunities to initiate conversations between families, relatives and care professionals about anticipatory end of life care planning and the implementation of appropriate support for both the relative and their family. The relative's final 'episode' of illness (leading to death) was often described as being: (1) accompanied by whole or partial mental incapacity for the relative; and (2) short in duration (hours, days or weeks). The interviewees reflected feeling shocked that the relative had died. Yet many families also described how the relative had been ill for a number of years, giving examples of the relative making several hospital visits and having contact with primary care staff.

In the next section we move on to consider the extent to which care professionals in either substance use or end of life care services recognised or responded to the individual relative's needs and/or the family's needs.

### 3.3 Family support needs and care services

The third main theme of the findings focused on family support needs and care services. Significantly, most interviewees discussed whether or not the family were present when the relative died. Circumstances of death varied, from the relative dying alone in their own home and not being found for a number of days, to the family gathered around the hospital bedside of the dying relative<sup>3</sup>.

Across the whole dataset (n=102), many family members reported being concerned about their relative's poor quality of life during their last few months of life. These included worries about their relative's wellbeing, particularly their levels of pain, distress and depression.

*My dad eventually managed to get a doctor to come and look at her [interviewee's mother]. They said there was nothing they could do, that she was very ill and she needed to go to hospital, and really put pressure on me - all of us - to try and talk some sense into my mum. And I just said: "I can't do that. She argues with everything I ever say to her. There is no way I am going to be the one that's going to be able to convince her." I could barely stay in the house, it was horrendous.*

Daughter aged 35 at time of bereavement.  
Mother died aged 63 years old.

Intensive medical intervention, combined with very distressing, rapid physical and mental deterioration, was described as causing particularly traumatic end of life experiences for relatives' families. Several families noted that this was compounded by years of feeling shame in relation to the relative's substance use. Linked to this, they recalled experiences of some care professional ignoring the relative and family when they asked for assistance. As the example below shows, the family were quite isolated, despite attempts to seek help from the GP:

*But she [Mother, wife of individual with an alcohol problem] did try a lot of things. She went to his doctor one day and you're not supposed to kind of discuss other patients with – his doctor couldn't really discuss him, but my mum sat in the surgery and said, "I'm not leaving until someone comes to see my husband." I think she sat there for an hour or so. And then someone said you need to deal with this woman. So she did try, but they kept saying: "We can't do anything unless he wants us to." He would not admit that there was a problem. ... They sent a few nurses, because of his legs, and that seemed to be while they were needing to sort the – dress his*

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<sup>3</sup> As a reminder, no deaths in the original research project occurred in a hospice setting – see Table 1 detailed earlier in this report.



*legs. And they dealt with his legs and he had creams and things. But not [any help] for alcohol and no doctor visited.*

Daughter aged 9 at time of bereavement.  
Father died aged 45, from chronic alcoholism.

Families said they anticipated they would be shown limited, if any, empathy/sympathy by hospital staff because previous interactions with health and social care staff in relation to their relative had led them to believe that they were stigmatised. Families also described feeling embarrassed about the relative's substance use and their relative's deteriorating wellbeing, describing how being on a hospital ward with limited privacy was highly distressing for the family and the relative:

*He was just lying there. You could hear from the noises he was making he was in pain. You know, his eyes had become really blood shot. And then over the seven days you saw him degrade literally. It was just taking over his body to the point where the last time I saw him his breathing was so far in between it was really, really scary. Like literally I thought at any second he was going to die. He was very, very yellow. He had a colostomy bag as well, which I absolutely hated. I just... there was no dignity with the way he died.*

Niece aged 19 at time of bereavement.  
Uncle died, aged 45, from liver failure.

When giving such examples of feeling embarrassed and concerned about a relative's discomfort, families noted that if hospital staff had experience of working with people with alcohol and drug problems, they were more likely to have an insight into the issues involved. They were also more likely to be empathetic and compassionate towards the relative and their families.

One interviewee described how her dying husband had been placed on a ward where there was a loud TV showing a Formula One car race. Her husband was experiencing discomfort, but he was unable to go in a private room because it was allocated on a 'first come, first served' basis and another patient was already in it. In desperation, her husband tried to make himself somewhere quiet and lay down in the bathroom:

*What he did in the end was he got out of bed. He actually leapt out of bed. Out of nowhere he just managed to get to the toilet, to the bathroom, and I followed him and he said, 'I'm not coming out. I'm going to stay in here. Get me a towel. Get me a towel.' And then he left and he went and he just tried to make himself a bed in the bathroom. And I came out and said, 'He's really suffering.' He just wanted to be private. 'He needs dignity'. And they said, 'Well he can't have dignity.' And I said, 'Why can't he go in that room?' 'Well because there's someone else in there.' I said, 'But that person doesn't need the room.' And in the end I went up to the man, 'Do you mind? My husband is actually dying.' He said, 'No, of course not. I don't mind at all.' And so I said, 'He wants to change beds.' So I managed to get him the room, but I had to force it because they couldn't care less.*

Wife, talking about her husband's death from hepatitis C

Many of the families described becoming socially isolated over the years, noting that they did not want to disclose full details of the relative's substance use to friends, other family members and neighbours, and so withdrew from many potential sources of informal support<sup>4</sup>. The extended family was often described not as a source of on-going support, but rather a site of conflict with different family members interpreting and responding to their relative's substance use in divergent ways. In families where alcohol/drug use was common among many family members, this was particularly apparent. As with all families facing a relative's death, individual family members may interpret and respond to the situation differently, with some refusing to believe that end of life is imminent. But in the case of families of people with alcohol/drug problems, such fragmented perspectives were described as exacerbating the already high levels of emotional strain that families have been experiencing, sometimes over a number of years.

*I didn't enjoy afterwards [following the funeral]- when the relatives came round - because they'd never bothered with us and probably for the same reason: because they knew mum was drinking. So they would never bother with us.*

Daughter, aged 55 at time of bereavement.  
Mother died aged 84, from multiple organ failure

Many families explained that because they were unclear that the relative was nearing the end of their life, they had been left with some regrets about their relationships and conversations with them. They described fractured family relationships, sharing examples of conflicted feelings, which were associated with wanting an opportunity to say their 'sorrys' or 'goodbyes' to each other. Some families had not discussed unresolved disagreements with the relative, feeling that their resentment about the relative's substance use was not appropriate at that time. For instance: one daughter who had been fostered at the age of twelve, described the range of emotions she went through as she stood at her birth mother's hospital bed, knowing she had only hours left to live:

*It was the first time I had seen her since I was twelve you know ... I was looking at her and you know a lot of mixed feelings were going through. And she had tubes, all these things going into her. And I thought 'Will I be nice? Or will I just you know ...' Because like I said, when I was standing there, I was wanting to be bitter ... But I had so much mixed feelings and I had my foster mum beside me holding my hand and the more I kept looking at her the more you know angry I was getting. My fist was like this – you know, clenched and that. And I thought: 'What's the point, you know? She is going to die. There is no point being angry and shouting and that you know.' But when I looked at her, I just, a lot of memories were coming back and the way I used to see her ... coming back from pubs and coming back with drink and sitting there with needles and that in her arms and you know*

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<sup>4</sup> Although it is important to note that many families do seek support from others only to find that it is not helpful, or is offered in a way that further undermines their situation. See further: Orford, et al., (2010).

*a lot of upsetting things would come back in my head. But you know it's, but no I just took her hand and I didn't want that, I said the goodbye I had wanted to give her. I said 'Goodbye.'*

Daughter aged 25 at time of bereavement.

Estranged mother died aged 40.

Some interviewees described wanting to communicate with health and social care staff (such as GPs, social workers, hospital nurses, counsellors or alcohol/drug workers) about their own needs arising from having a family member with problematic substance use. Families noted that their own health and social care wellbeing were often unrecognised by the relative, health and social care professionals, or even by themselves. In some cases, families expressly stated that they wished they had been encouraged by the health and social care professionals caring for the relative to make opportunities to express their feelings about their relative (and their substance use) both prior to, and after, the relative's death.

*There was that Doctor who wouldn't help me, and I really was in a terrible state, you know. I couldn't eat, I couldn't sleep but I kept on the go all the time, my stomach used to turn over and I could hear my heart beating you know. I would go to sleep for a couple of hours, wake up, go in and see if he [son] was alright.*

Mother aged 68 at time of bereavement.

Son died aged 49 from acute alcohol toxicity.

Despite families describing a range of feelings about the relative, their substance use, the relationship between them, and the relative's death, many families said they had limited, if any, offers of health or social care support for themselves - either prior to, or after bereavement. A few families gave examples of asking for support, help and advice for their own needs from a range of health and social care services. These included families asking GPs for anti-depressants, counselling or referral to support groups for families of drug and alcohol users. In one instance, a mother described asking her children's school for pastoral support for her daughter who was being bullied for having a 'junkie dad':

*Her older brother was saying she's [sister] really distressed. She's on her own in the playground. No one will talk to her ... she was getting aggressive and so they just banned her from part of the playground. And it was just getting worse and worse. ... They did get someone in to help her - a counsellor - but they couldn't, the counsellor couldn't work with her: she was 'obstructive'. And in the end they called me out. After a long while they called me in and said they couldn't work with her and I told them what these kids in the playground were doing. And she said, 'I didn't know.' I said, 'Well I've been coming in and complaining.' And she said, 'Well now I know that, I can do something about it.' And she did and she got one-to-one tuition and she got help. She made big strides. She was better integrated.*

Wife aged 46 at time of bereavement.

Husband died aged 39, from Hepatitis C.

Overall, it is apparent that families of relatives with alcohol and drug problems who are approaching the end of life are often in desperate need of support for their own health and social care needs - as well as the needs of the relative. The interview evidence suggests that families have often sought varied help and support over the years, with limited positive experience and multiple missed opportunities by care professionals and varied services to recognise and respond to the relatives' and families' wide-ranging needs. Families expressed feeling isolated from care services and stigmatised by care professionals. They conveyed their limited expectations of having their support and care needs met by either care professionals or informal support networks (such as friends, neighbours and other family members). Other families under prolonged strain, who had struggled to know how best to respond to the relative's substance use, had rarely spoken to care professionals, friends, neighbours or other family members about their own support needs. With these points in mind, we now turn to the discussions and conclusions section of the report. We explore the implications of these findings from the secondary analysis for the interview fieldwork in phase two of this research strand on families' experiences of end of life care for relatives with alcohol and drug use problems.

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## 4. Discussion and conclusions

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The following section discusses the key findings from the secondary analysis focusing on the three main themes, namely: end of life care; missed opportunities for end of life and/or substance use care; and family support needs.

In terms of end of life care, we found that only 18 out of 93 deaths described included care professionals identifying and communicating the relative's end of life care to the families. A small number of interviewees described how their relative refused medical treatment to the point that they lost consciousness. Many of the families suggested the relative denied, either explicitly or implicitly, that they might die to both care professionals (including GPs, social workers and hospital nurses) and their families. It is important to recognise the challenges that this poses for care professionals, as they may identify the relative's end of life and consider what appropriate care should be put in place (and when), but they must respect the wishes of the relative. This includes care professionals keeping end of life care information from families unless the relative consents for this information to be shared with them.

Overall, this secondary analysis raises the question: how can we better understand family experiences of end of life care for relatives with alcohol and drug use problems? This is not without its challenges, not least because relatives may not want to talk about their end of life care to their families. Sometimes this may be the relative's fear of causing pain to the family, or it may be the relative denying their imminent death. Some families may not be privy to information shared between care professionals and relatives about the person's end of life due to consent and confidentiality issues.

Even where an exact prognosis by the care professionals is impossible – which may be the case particularly for alcohol-related liver disease – relatives and families could have benefited from explicit discussion amongst themselves and care professionals about the possibility of an end of life situation. This would have allowed some families to prepare themselves for the worst and provide an opportunity for reflections about care preferences and end of life conversations with the relative. Without such warning, families sometimes expected another 'bounce-back' from a health crisis, such that when death occurred, they questioned whether 'everything possible' was done to save the relative.

As described in some of the interviews, the relative's death may have been extremely distressing to witness for families - in part due to the families' limited knowledge of the symptoms and treatments that often arise for people who have alcohol and/or drug problems. This meant families felt shocked and extremely upset that the relative was unable to have the peace, privacy and dignity that the family would have liked them to have as they died. Unprepared for either the relative's rapid deterioration or intensive hospital treatments, the families' feelings of shame and stigma were often exacerbated.

End of life and bereavement can stir difficult emotions such as regret and guilt for all families – but particularly among those related to individuals with substance use problems. Despite the interviewees describing the impact that the relative's end of life had on the wider family's wellbeing, the families described very few experiences of either formal (from care

professionals) or informal care or support (from neighbours, friends, family members, bereavement charity Cruse, and other third sector organisations) for their own needs. This was despite many families describing attempts to seek help, care and support for their own needs during the years leading up to their relative's end of life, as well as after their death. Only a few examples were given of GPs prescribing family members anti-depressants or referring them to counselling or support groups for families of drug and alcohol users, in response to requests for bereavement support.

A small number of families described ways in which care professionals recognised and responded to them positively, including: hospital nurses speaking words of comfort, and practising compassion by organising a private room away from the hospital ward for the family to grieve. However, most interviewees suggested care professionals, and health and social care services, fell short of recognising and responding to the magnitude of their feelings about their relative, the relative's substance use, their relationship with them and the relative's end of life.

With these issues in mind, the findings from this secondary analysis informed the design and delivery of the primary qualitative data collection with families in phase two of this focus on families. Phase 2 aims to develop a greater knowledge and understanding of how families of individuals with alcohol/drug use problems experience the relative's end of life and the extent to which services can recognise or respond to the whole family's needs in the future.

With large proportions of people with substance problems never accessing services and so remaining a 'hidden population', we recognise that the experiences of our sample may not be representative of families of people with alcohol and/or drug problems. Indeed, the diversity of experiences described by interviewees makes it difficult to extract overarching findings in a brief way. However, the diagram presented in Figure 3 (below) attempts to summarise the sequence of key events as described by many interviewees. This highlights the range of issues that can impact upon families' attitudes to, and experiences of, end of life care for their relative:



Figure 2: Summary of family experiences of a relative's problematic substance use and health needs

Many end of life situations for relatives with alcohol problems will take place in a hospital setting. So for many of them and their families, making the hospital environment as fitting for end of life care as possible is a priority. For others, it may be possible that, where appropriate, joined-up working practices allow people to die at home or in a hospice. As the interviews reveal, even among the cases where deaths were anticipated by care professionals, the opportunity to discuss end of life care explicitly was rarely taken. Yet the interviews do provide initial insights into some of the factors that may be associated with good end of life care for families.

Primary among these insights was the need for families and relatives to be able to have trust in the skill, experience and compassion of care professionals. Family members described feeling more positive about the relative's end of life hospital experiences if they felt staff had compassionate interactions with the relative and themselves, and understood the needs of individuals with alcohol/drug problems and their families. In this sense, care professionals who openly discuss substance use and explicitly recognise the long-term stress families may have been experiencing may be able to counteract some of the feelings of shame or stigma that the whole family experience - thus also facilitating better working relationships between care professionals, families and relatives.

In a hospital environment, families may need to hear from care professionals that they can spend as much time as possible with the relative, helping the relative feel as comfortable and relaxed as possible at the end of their life. Many interviewees described the conflicting emotions that they experienced as the relative approached the end of their life. It is important that care professionals recognise both this and the particular importance that friends or extended family may have for a patient (who may have a more meaningful relationship with them than with their immediate family). Families also need to be advised by care professionals that certain bereavements (such as those of people who use alcohol/drugs; sudden, premature deaths; people who have committed suicide or been murdered etc.) can be particularly difficult to experience – and the provision of information about sources of support for the family (along with encouragement to actually pursue these options) can be extremely helpful. The needs of any children warrant specific consideration, including: how much they should be told (and how); whether they should be present during end of life conversations; how much of the treatment/dying process they should witness; and what support they need to say goodbye.

Families may benefit from encouragement to talk and make peace with the relative (and sometimes each other): helping them to come to accept their approaching end of life. Some interviewees described needing a degree of support to let go of feelings of anger and say their final goodbye. Recognition by relatives, care professionals and families themselves, of the strain that the whole family have been under and the frustration and fears that they have been experiencing not only shows compassion for their situation, but may actually facilitate improved communication and a crucial degree of openness and tenderness in the last hours of a person's life.

In bringing these discussions and conclusions together below we have summarised the dynamic between family life, help-seeking and end of life experiences in Figure 4. Following



that summary we turn, in the final section of the report, to briefly present the implications of this analysis for fieldwork in phase 2.

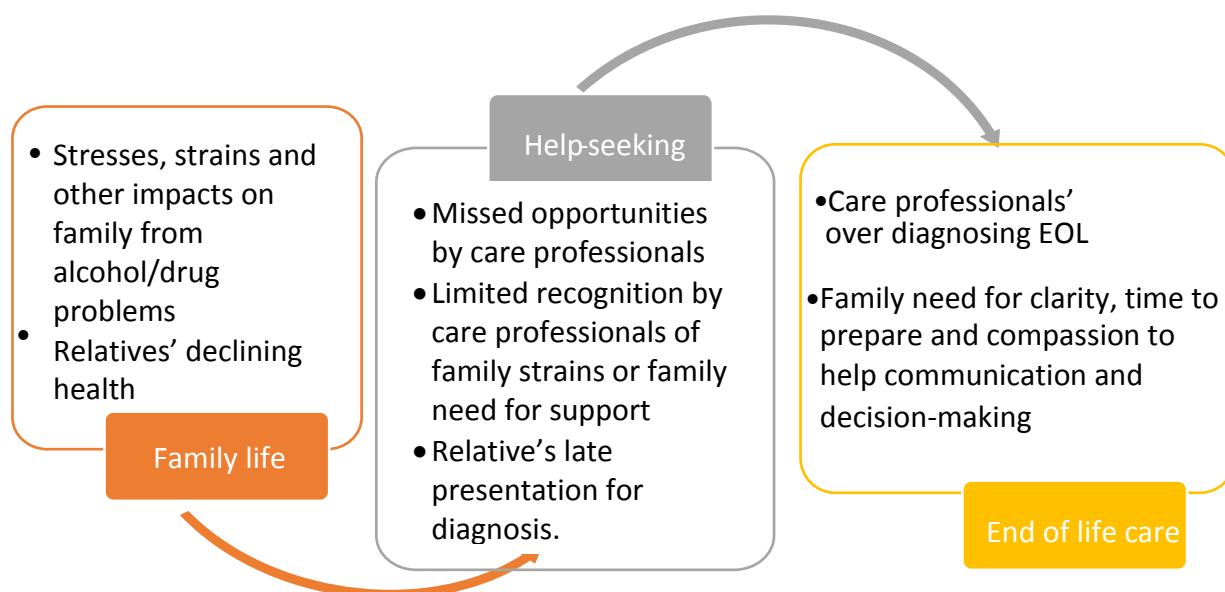


Figure 3: The dynamic between family life, help-seeking and end of life experiences

#### 4.1 Implications for fieldwork in phase 2

As discussed above, this secondary analysis has identified several key issues which will inform the focus of our phase two interviews with families of relatives with life-limiting conditions and alcohol/drug problems. As well as asking about their experiences of their relative's end of life<sup>5</sup>, the primary data collection will explore both the families' experiences and needs, and how these fit within the experiences and needs of the relatives.

It is important to remember that this secondary analysis draws upon interviews from a study of bereavement through substance use – with a specific sampling strategy and limited focus upon end of life care. As a result, we cannot say that any conclusions we have drawn are more widely generalisable, as they may well be a feature of recruitment, the self-selecting nature of that interview sample, and the specific focus of the original research questions. However, they have provided a wealth of data to inform our phase two interviews with families. One function of the phase two new data collection will be to verify some of these findings from the secondary analysis. Indeed, the findings of this secondary analysis have provided a very helpful springboard for moving on to our primary data collection: enabling us to underpin our fieldwork interviews with the insight and questions generated by these ideas.

<sup>5</sup> For example: What is going/went well; What helps/helped; What isn't/didn't go well and why; and What would help etc.

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## Appendix

**Table 2: Comparison of key demographic characteristics of the six sub-groups**

	Identified end of life  <i>Category 1</i> (n=6 deaths)	Anticipated hospital death upon loss of capacity  <i>Category 2</i> (n=12 deaths)	Hospital death that could have been anticipated  <i>Category 3</i> (n=6 deaths)	Home death that could have been anticipated  <i>Category 4</i> (n=10 deaths)	Sudden, possibly foreseeable death  <i>Category 5</i> (n=16 deaths)	Sudden, unpredictable death  <i>Category 6</i> (n=43 deaths)
Interviewee's location	83% England 17% Scotland	75% England 25% Scotland	100% England 0% Scotland	80% England 20% Scotland	63% England 37% Scotland	53% England 47% Scotland
Gender of deceased	83% male 17% female	67% male 33% female	50% male 50% female	60% male 40% female	81% male 19% female	91% male 9% female
Deceased's relationship to the interviewee	Partner - 2 (Adult) Child - 2 Parent - 1 Sibling – 1	Parent - 7 (Adult) Child - 2 Sibling - 1 Partner – 1 Aunt - 1	Partner - 1 Sibling - 1 Parent - 3 Uncle – 1	(Adult) Child - 3 Sibling - 1 Parent - 5 Friend – 1	(Adult) Child - 10 (Ex-)Partner - 3 Parent - 1 Friend – 2	(Adult) Child - 27 Partner - 6 Sibling - 7 Parent - 1 Friend – 2
Alcohol/other drug use	50% alcohol only  50% alcohol and drugs	83% alcohol only  17% alcohol and drugs	83% alcohol only  17% alcohol and drugs	40% alcohol only  30% drugs only 20% alcohol and drugs 10% OTC	13% alcohol only  69% drugs only  19% alcohol and drugs	9% alcohol only 1 alcohol and trx  67% drugs only  8 alcohol & drugs 1 butane gas
Age of the deceased	Mean 42 years (Range 30 - 54 yrs)	Mean 48 years (Range 20 - 63 yrs)	Mean 62 years (Range 45 - 82 yrs)	Mean 48 years (Range 34 –64 yrs)	Mean 35 years (Range 20 - 54 yrs)	Mean 30 years (Range 16 - 51 yrs)

**Table 3: Comparison of key end of life factors for the six sub-groups**

	Identified end of life  <i>Category 1</i> (n=6)	Anticipated hospital death upon loss of capacity <i>Category 2</i> (n=12)	Hospital death that could have been anticipated <i>Category 3</i> (n=6)	Home death that could have been anticipated <i>Category 4</i> (n=10)	Sudden, possibly foreseeable death <i>Category 5</i> (n=16)	Sudden, unpredictable death <i>Category 6</i> (n=43)
<b>Place of death</b>	83% in hospital (n=5 of 6) 1 home death	100% hospital	100% hospital	100% at home	11 at home 5 other domestic 3 outside 1 hospital 1 police station	17 home 10 other domestic 6 outside 5 other 5 unstated
<b>Condition warranting treatment/ intervention</b>	2 cancer diagnoses 1 Hepatitis C 1 HIV 2 liver cirrhosis	6 liver disease Tuberculosis Encephalitis Kidney disease Hep B and C Blood clot on lung Heart attack & stroke	Diabetes Schizophrenia Depression Alcoholic pancreatitis; Alcohol-related liver disease Hepatitis	Alcoholic ketosis of the liver (& diabetes) 2 liver cirrhosis Stomach ulcers 2 liver failure Septicaemia (coronary) B	Chronic kidney failure; Brittle asthma Mental health treatment Chronic life stressors and/or behavioural changes suggestive of imminent death	Behavioural issues, chronic life stressors; Recent changes in tolerance.
<b>Duration of final medical intervention</b>	Several hours to 2 months (average 6 days)	Several hours to 30 days (average 14 days)	3 – 42 days (average 8 days)	N/A	N/A	N/A
<b>Point at which family informed of relative approaching end of life</b>	As above, except a man with Hep C diagnosed 3 years prior to death	As above	Families generally shocked at rapidity of decline and ultimate death	None - but three interviewees concerned about imminent death risk	N/A	N/A
<b>Relationship between death and alcohol/drug use</b>	2 direct alcohol-related deaths  2 chronic drug related deaths	8 direct alcohol-related deaths 2 drug overdoses 1 chronic drug-related death (Hep C) 1 indirect alcohol-related death	3 direct alcohol-related deaths 1 chronic drug-related death (Hep C) 1 indirect alcohol-related death 1 unclear	7 direct alcohol-related deaths 1 chronic drug-related death (Septicaemia) 1 indirect alcohol-related death 1 drug overdose	9 drug overdoses 5 suicides 1 overdose alcohol medication 1 alcohol withdrawal	23 drug overdoses 7 suicides 5 fatal accidents 3 aspiration of stomach contents 1 alcohol poisoning 1 pulmonary embolism 1 seizure, 1 murder

**Table 4: Sub-sample of participants describing missed opportunities for intervention**

Family situation	Narrative summary	Missed opportunities to intervene
<p>1. Interviewee: Wife, aged 46 at time of bereavement (2001)</p> <p>Deceased was male, aged 39, died from Hepatitis C</p> <p>Three young children</p> <p><b>Identified end of life group (Cat 1)</b></p>	<p>The interviewee's husband had used alcohol/drugs problematically for many years and had Hepatitis C. The interviewee talks about a three year of 'end of life phase' (although it is unclear whether this was diagnosed formally, or simply defined by the interviewee). She describes how her husband refused to admit he was dying. Eventually he went into hospital because he was bleeding from several sites. Whilst the family had received some practical help from an unspecified source to tile the bathroom to minimise the risk of infection, no other formal support (including palliative or end of life care) was mentioned, despite substantial support needs and despite the interviewee knowing that her husband was likely to die. Little/no informal support was received from the husband's parents, although her parents provided some money to buy a better bed.</p>	<p>No palliative care described although Hep C diagnosed and liver transplant declined</p> <p>Multiple A&amp;E visits, but none triggered any ongoing support</p> <p>Children unsupported although school aware of daughter's behavioural changes</p>
<p>2. Interviewee: Mother, aged 58 at time of bereavement (2002)</p> <p>Deceased was male, aged 39, died from organ failure</p> <p><b>Identified end of life group (Cat 1)</b></p>	<p>The interviewee's son was a drug user and HIV+. He died in hospital as he was too ill to be discharged or to discharge himself as he had done before. Despite this, there is no mention of palliative or end of life care.</p>	<p>No palliative care described although HIV diagnosed</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>3. Interviewee: Daughter, aged 38 at time of bereavement (1997) Deceased was male, 54 years old, living in a care home until the day he died. Four adult children</p> <p><b>Identified end of life group (Cat 1)</b></p>	<p>Despite a difficult and abusive relationship with her father over many years, this interviewee was the main carer for him after his wife died. Approximately two years before he died he moved to a nursing home (where the staff knew about his alcohol use and watered down his whisky) although he actually died in hospital. There is no mention of professional communication or support about palliative or end of life care (from either the nursing home, or the hospital) until the last day of her father's life.</p>	<p>No palliative care or preparation for end of life described.</p>
<p>4. Interviewee: Father, aged 57 at time of bereavement (1996) Deceased: Son aged 30, living alone</p> <p><b>Identified end of life group (Cat 1)</b></p>	<p>The interviewee describes his son as being in intensive care for two weeks before dying as a result of his longstanding alcohol problem. The interviewee (and his wife who was also interviewed separately) anticipated that his son would die during this hospital stay and described the hospital staff as "brilliant". However, the interviewee did not make any mention of end of life care so it is unclear whether this is a general comment or something more specific to care because the man's son was dying.</p>	<p>No palliative care or preparation for end of life described.</p>
<p>5. Interviewee: Step-sister, aged 50 at time of bereavement (2008) Deceased: Male aged 45. Two children and an ex-wife</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee only became aware of her step-brother's alcohol use when he was admitted to hospital for a few months. No conversations with him or his family about the possibility of premature death or the need to consider palliative or end of life care He was subsequently home alone when oesophageal varices burst. Lodgers found him and called an ambulance, but he refused to go to hospital. He was eventually taken to hospital, but had sustained brain damage and died hours later. Step-sister was abroad when he died.</p>	<p>No discussion with family about problematic alcohol use, or raising awareness of risk of premature death described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>6. Interviewee: Daughter, aged 9 at time of bereavement (1998)</p> <p>Deceased: Father, aged 45 years.</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee describes being aware that her father had started drinking heavily two years before his death and of him developing clear physical symptoms of alcohol problems and deteriorating prior to his death. Help sought after he had a fit at home. The interviewee's uncle encouraged his brother to go to hospital where he was for a week before dying. Despite this man having clear and advanced problems as a result of his drinking it seems that there were no conversations or support about palliative or end of life care. The interviewee and her brother were at school when their father died, their mother having decided not to let them see him die.</p>	<p>No conversations or support about palliative or end of life care described.</p>
<p>7. Interviewee: Mother, aged 51 at time of bereavement (2007)</p> <p>Deceased: Son, age 20 years</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee described how her son collapsed (as a result of his alcohol and heroin use) and being taken to intensive care where he was described as 'brain dead'. The family agreed to turn off his life support machine 8 days later. Health professionals advised the interviewee and her family to go home from hospital which meant they missed their son's death. It seems that there were no conversations about palliative or end of life care. Furthermore, by the time it was clear that this man was dying he was not mentally capable of having such conversations with his family.</p>	<p>No conversations or support about palliative or end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>8. Interviewee: Husband, aged 64 at time of bereavement (2010) Deceased: Wife aged 55</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee's wife had a longstanding alcohol problem and was diagnosed with liver damage. She completed treatment but slowly started to drink again. The interviewee describes how his wife had a fall and was taken to hospital in a coma - she was given 48 hours to live but died 5 days later. Despite a clear diagnosis of liver damage/disease it appears that there were no conversations about this or discussions /plans around end of life care.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>9. Interviewee: Daughter, aged 35 at time of bereavement (2011)  Deceased: Mother, aged 63</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee's mother had had an alcohol problem for many years. Eventually, despite repeated attempts by the interviewee to get help from a GP and have her mother admitted to hospital, the interviewee's mum was admitted to hospital where she died a few days later. There is some despair that the GP did not offer care and support or recognise how serious the alcohol problem was (which could have led to conversations about this and the potential for there to be discussions and plans around palliative and end of life care). It also seems that there were no such conversation or support from hospital staff although they did move the woman from a ward to a private room.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>



Family situation	Narrative summary	Missed opportunities to intervene
<p>10 Interviewee: Daughter, aged 16 at time of bereavement (2005)</p> <p>Deceased: Father, aged 50</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee's father had a longstanding alcohol problem. Following her father's liver shutting down and loss of bladder and bowel control he was admitted to hospital where he had a stroke and shortly afterwards caught pneumonia. He was in hospital for another month before he died. Despite opportunities which must have arisen (because of the longstanding nature of the problem and the health problems that no doubt accompanied this) it seems that the first conversation about end of life occurred on the morning that her father died. The interviewee said, "<i>We had a phone call at 8 in the morning saying, 'Look we think he's going to die'. And mum said, 'You know, how long have we got to get there?'....and they said, 'Oh yes, just as long as you're here before lunchtime'....15 minutes later [we had a] phone call that he'd died</i>". In terms of formal support the interviewee felt that care for her family and support for her when she visited the hospital was poor with the exception of an individual nurse who knew the family and offered words of comfort.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>11 Interviewee: Son, aged 31 at time of bereavement (1990)</p> <p>Deceased: Father aged 49 years</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee's father had a longstanding alcohol problem and spent 3 weeks in hospital in a coma before his life support machine was turned off. There is no detail about any communication about end of life or end of life care so we assume that such conversations did not take place and that no palliative care or end of life care was offered. Despite the longstanding nature of the alcohol problem it seems that no conversations occurred before the final episode of this man's life.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>12 Interviewee: Niece, aged 37 at time of bereavement (2013)</p> <p>Deceased: Aunt, aged 50</p> <p><b>Health intervention once lacking capacity (Category 2)</b></p>	<p>The interviewee explains that her aunt was found collapsed in the street and admitted to hospital with kidney failure and TB. She was in hospital for a number of weeks and the interviewee notes that she was “well looked after by the nurses”. Although health professionals communicated some signs of improvement and recovery, her aunt deteriorated and the family had to decide to turn the life support machine off. Despite the family being aware that their relative was probably going to die there is no/little mention of end of life care from the hospital staff during these last few weeks.</p>	<p>No/little mention of end of life care from the hospital staff.</p>
<p>13 Interviewee: Son aged 19 and daughter aged 17 at time of bereavement (2008)</p> <p>Deceased: Father aged 49</p> <p><b>Hospital death – could reasonably have been anticipated, but not identified (Category 3)</b></p>	<p>During a family holiday the interviewees’ father, who had a longstanding alcohol problem, became ill. On return the GP advised him to go to hospital where he underwent 3 weeks of dialysis but then died of multiple organ failure. Both siblings describe their feelings of “false hope” and of being shocked by their father’s death and being seemingly unaware of the severity of his condition. Describing their difficulty in understanding what their father was saying in last days, they say they regret not being able to respond to his wishes. Neither interviewee identified any offer of support for them or the family which is a particular shame given that he became too unwell too communicate some of his last wishes to his children.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>14 Interviewee: Daughter aged 55 when bereaved (2010)</p> <p>Deceased: Mother aged 84</p> <p><b>Hospital death – could reasonably have been anticipated, but not identified (Category 3)</b></p>	<p>The interviewee describes her mother, who had a longstanding alcohol problem, falling at home and not being found for a week. She was admitted to hospital where she died a day later of multiple organ failure. End of life was not discussed explicitly by nurses, instead they explained that her mother was ‘poorly’. One nurse said she wasn’t working over the weekend and when she finished her shift on the Friday told the interviewee that she (the nurse) wouldn’t see the patient again, giving a sense of imminent death which had not been explicitly communicated to the interviewee. However, the interviewee said that her mother was put in a side ward with only one other patient and they were given plenty of time alone before death. Despite previous attempts to access both formal and informal support for both her mother and herself, she felt both were inadequate – such conversations could have led to a recognition of the potential need to discuss palliative care.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>15 Interviewee: Niece aged 19 at time of bereavement (2008)</p> <p>Deceased: Uncle aged 45 years</p> <p><b>Hospital death – could reasonably have been anticipated, but not identified (Category 3)</b></p>	<p>The interviewee said that her uncle was told he would die unless he stopped drinking three years prior to his eventual death. Despite this, it seems that there were no conversations about his condition and the need to consider palliative or end of life care. Eventually, following liver failure her uncle was admitted to hospital where he died a week later. The niece felt the end of her uncle’s life was rapid and said that she was shocked at his death and unaware that his condition was terminal. This distress could have been minimised if earlier opportunities had been taken to discuss the risks associated with alcohol liver disease including the potential need to consider palliative and end of life care. However, the interviewee did praise the care from the hospital staff although it is unclear what might have been specific to end of life.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>16 Interviewee: Step-sister, aged 58 at time of bereavement (2008)</p> <p>Deceased: Step-sister aged 61</p> <p><b>Hospital death – could reasonably have been anticipated, but not identified (Category 3)</b></p>	<p>The interviewee said that her step-sister had a history of hospital admissions associated with her alcohol use, and had been declined a liver transplant four months before death because she was too unwell. Despite the severity of the alcohol problem, it seems that there were no discussions about the potential need for the family to consider palliative and end of life care, despite repeated interactions with hospital staff (including liver transplant teams). The family thought their relative would recover, with the interviewee suggesting there were no explicit discussions around end of life. She explained, <i>“When we were in and out of A&amp;E, maybe we could have done with some help, or advice or somebody [speaking] to us and say look, you know, it’s obvious your sister’s got this problem, have you tried this, you know or have you tried contacting this organisation, or this, whatever, if there’s help available, kind of make it aware”</i>. However, despite this, the interviewee said that the hospital staff were understanding and supportive about allowing relatives (and a close friend of the dying woman) to visit and say their goodbyes.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>17 Interviewee: Mother aged 68 at time of bereavement (2012)</p> <p>Deceased: Son aged 49 years</p> <p><b>Home death – could reasonably have been anticipated (Cat 4)</b></p>	<p>The interviewee talks about her son being discharged from hospital the week before he died, and of having struggled for many years with his drinking and of being <i>“frightened all the time he was going to die”</i>. Yet it seems that there were no conversations about the severity of the alcohol problem and the possible need to think about palliative or end of life care.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>18 Interviewee: Daughter, aged 17 at time of bereavement (1996)</p> <p>Deceased: Mother aged 41 years</p>	<p>This daughter said that it said <i>‘cirrhosis of liver’</i> on her mother’s death certificate, yet it seems that there were no conversations about her severity of the alcohol problem and the possible need to think about palliative or end of life care.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p><b>Home death – could reasonably have been anticipated (Cat 4)</b></p>		
<p>19 Interviewee: Daughter aged 33 at time of bereavement (2011)</p> <p>Deceased: Mother aged 64 years</p> <p><b>Home death – could reasonably have been anticipated (Cat 4)</b></p>	<p>This interviewee describes a cycle of there being numerous interactions with GPs, hospitals and community services because of her mothers' longstanding alcohol use. Doctors had told the interviewee that, <i>"If she goes back to drinking, it may not be recoverable"</i>. Yet it seems that there were no conversations about her severity of the alcohol problem and the possible need to think about palliative or end of life care.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>
<p>20 Interviewee: Mother, aged 68 at time of bereavement (2006)</p> <p>Deceased: Son aged 36 years</p> <p><b>Home death – could reasonably have been anticipated (Cat 4)</b></p>	<p>The interviewee says her son became increasingly dependent on her and had refused treatment previously. She conveys feelings of disappointment and anger in health professionals suggesting that the doctors had become fed up with her son and left him at home where he died on her settee. It could be assumed from this that opportunities were missed to highlight the severity of the problem and to offer conversations around palliative and end of life care. The interviewee felt that her son should have been in hospital but because the health practitioners knew she was caring for him, they shied away from helping.</p>	<p>No conversations about alcohol use or discussions /plans around end of life care described.</p>

Family situation	Narrative summary	Missed opportunities to intervene
<p>21 Interviewee: Mother, aged 53 at time of bereavement (2013)</p> <p>Deceased: Son aged 34 years</p> <p><b>Home death – could reasonably have been anticipated (Cat 4)</b></p>	<p>The interviewee describes on-going episodes of illness and help seeking treatment by both her and her son for his addiction. She notes her son was in denial despite warnings from health professionals who felt he was ignoring their health advice: <i>“And he [Dr] said ....I am giving you this warning, you better, your liver won’t restore you, ...and they told him they said you will need to stay off these things because if it happens again you know what the next step is going to be, death. He said I am really shocked that you are even sitting here with the amounts you have been taking in the past. Because he was in two or three times and the doctors were just sick of him. “Oh you are just not listening”. However, it seems that these direct warnings were not accompanied by any conversations about future needs/plans including palliative and end of life care.</i></p>	<p>Warnings about risk of dying from continued over the counter drug misuse not followed up.</p>